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Social participation and employment status after kidney transplantation: A systematic review

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Abstract

Objective: To summarize and assess literature regarding social participation of recipients after successful kidney transplantation. **Methods:** A systematic review including a literature search in Medline (1980–2003) and five other databases, and assessment of methodological quality of selected studies by two reviewers applying a checklist of twelve criteria. **Results:** Seventeen studies out of 1443 identified references were selected. Quality scores for internal validity ranged from 0% to 50% (median 20%). Employment was the most used indicator of social participation and two studies briefly reported on vacation and recreation. Employment rate ranged from 18% to 82%, however differences in defining categories of employment or lack of description were present. Study populations were heterogeneous with regard to demographic and clinical characteristics. Three studies identified pre-transplant employment status as predictor of post-transplant employment. Other potential risk factors were not consistent across studies. **Conclusion:** Measurement of social participation focuses mainly on employment status. Quality assessment revealed shortcomings in reporting and validity of studies, whereby valid conclusions regarding the degree of social participation after kidney transplantation cannot be drawn. Future research should supplement the focus on employment status by examining other aspects of social participation as well as potential risk factors.

Key words: Employment, Kidney transplantation, Rehabilitation, Social participation, Systematic review

Introduction

Half a century ago, in 1954 the first successful human kidney transplantation was a fact [1]. Kidney transplantation can be seen as one of the success stories in medicine during the 20th century and nowadays has become a routine procedure and treatment of choice for end-stage renal disease (ESRD) [2]. As a result of the growing cost of

health care the assessment of outcome of medical treatment became common during the last two decades, also in the field of renal disease. Wolfe et al. [3] demonstrated for the first time the advantage of transplantation in terms of survival and longevity compared to dialysis. Kidney transplantation is also considered the most cost-effective treatment modality for ESRD [4, 5]. Besides clinical and economic parameters, the

patient's subjective experience in terms of satisfaction and quality of life became an area of intensive investigation. A wide range of assessment scales demonstrated higher levels of functional capacity for patients after successful transplantation compared with patients on dialysis [6]. A variety of studies showed an increase in quality of life after transplantation [7–11].

The incidence of renal replacement therapy (RRT) for ESRD rose rapidly in the European countries from 79.4 per million population (pmp) in 1990–1991, to 117.1 in 1998–1999 [12]. A world-wide study of 120 countries revealed an increase of 7% in treated ESRD patients between 2000 and 2001. The majority of patients was treated by dialysis and 23% received an donor organ [13]. A simulation model estimating the future demand for RRT in England predicts a further substantial growth of the RRT population [14]. In the Netherlands on January 1, 2005 there were 11551 ESRD patients, of which 5259 (46%) patients were on dialysis and 6292 (54%) patients were living with a functioning donor kidney (Source: Dutch End-Stage Renal Disease Registry, <http://www.renine.nl>).

Transition from dialysis to transplantation induces changes in daily life of recipients and requires adjustment and adaptation. Even though patients are successfully transplanted they have to comply with a strict therapeutic regime of medication and hospital visits, mostly accompanied by feelings of uncertainty due to the possibility of rejection or other causes of graft failure such as chronic transplant dysfunction. However, patients are no longer in need of dialysis and as a consequence save time and energy every day. Though the benefits of kidney transplantation on survival and quality of life are well studied, less is known about how people utilize this time and energy and if they are able to participate in regular or day-to-day activities and in society. Given the general agreement that quality of life is a multidimensional concept [15], social participation can be considered as an important indicator of quality of life. A component of social functioning often assessed in ESRD studies is employment status [16].

Therefore, the objective of this study is to systematically review and summarize current literature regarding social participation of recipients

after successful kidney transplantation. Participation in this study is operationalized as the way in which people contribute to society, such as participation in the labour force, schooling and education, leisure activities, volunteer work, household activities and social relations. As a consequence this study is restricted to actual performance of these activities, in other words what recipients actually do during their daily lives. Commonly used concepts of quality of life as subjective well-being, satisfaction and perceived limitations are beyond the scope of this review. Before patients are able to develop or regain activities after transplantation it takes time to recover and rehabilitate. Therefore this review focuses on mid- or long-term social participation after transplantation.

Methods

Identification of studies

The first author and an experienced medical librarian (see acknowledgements) developed an extensive search strategy based on keywords associated with the population of kidney transplant patients and the outcome variable social participation. Databases searched were MEDLINE (1980–2003), EMBASE (1989–2003), CINAHL (1982–2003), PsycINFO (1980–2003), International Bibliography of the Social Sciences (1981–2003) and the Cochrane Library. The lengthy search period was chosen because of changes over the years in the field of kidney transplantation and its potential consequences for daily life of patients. The search was restricted to articles published in the English language.

Keywords (Medical Subject Heading (MeSH) terms and textwords) used for finding the study population were: kidney-transplantation, kidney-failure-chronic, transplantation, end stage renal disease. Because of the lack of a clear definition of the outcome variable social participation and its relatedness to rehabilitation and quality of life, we considered it important to perform a sensitive and broad search strategy. Therefore keywords related to a variety of aspects of social participation were included. For MEDLINE the keywords were:

activities of daily living, adaptation, educational status, employment, exercise, health status, health status indicators, interpersonal relations, leisure activities, physical fitness, psychological stress, questionnaires, return to work, social adjustment, social behaviour, sports, vocational rehabilitation, work, work capacity evaluation, quality of life. Additionally, the keyword rehabilitation was not only used as a single MeSH term, but also as subheading in combination with keywords concerning the study population, and as free textword in combination with the MeSH terms treatment outcome and follow-up studies. If differences in terminology between databases existed, alternative keywords were identified by using the index or thesaurus of the concerning database. This resulted in search strategies with specific keywords for each database. (Full search strategy is available from the first author.)

The selection of the identified references was performed in a step by step process. First, a broad list of in- and exclusion criteria was developed to evaluate the potential relevance of the reference for the subject of this review. These criteria were applied in a pilot by two reviewers on 40 randomly selected references, whereupon revision took place. A repeated pilot of 20 references by three reviewers confirmed the appropriateness of the criteria. With this list an initial selection was performed by the first author based on relevance of title, keywords or abstract of the identified reference. Secondly, two reviewers (SvdM and BK) independently assessed the abstracts of the references identified during the first screening. If an abstract was not available or the abstract provided insufficient information, the full paper was obtained. This second phase resembled a dynamic process with frequent discussion about the criteria and their specific applicability, and resulted in further refinement and redefinition of the selection criteria. Eventually each reference was assessed according to these criteria. In case of disagreement between the two reviewers consensus was reached by discussion.

Ultimately a study was included if: (1) the study population either exclusively concerned adult patients with a functioning graft after kidney transplantation or enclosed an identifiable and separately analyzed subgroup of adult patients after successful kidney transplantation; (2) the

study population had a mean follow-up of at least 1 year after kidney transplantation; (3) the study presented sufficient information based on patient's self-reported data about variables considered to be indicators of social participation such as employment, return to work, schooling, household activities, leisure activities, social relations; (4) it concerned a full research report of an observational study, including description of the methods and measurements used, and characteristics of the study population.

A study was excluded if: (1) the study population solely consisted of patients with combined kidney-pancreas transplantation or solely included patients after retransplantation; (2) relevant variables did not represent the actual performance of participation, but merely the patient's own perception of social participation. Examples of such concepts are degree of satisfaction, well-being or happiness, perceived limitations or restrictions, and perceived ability to perform activities; (3) activity participation was measured as physical exercise or physical activity, for reasons that this only encompasses the physical aspect and not the social aspect of participation; (4) employment status of the study population was the only indicator presented concerning social participation, and merely described as a demographic characteristic.

Reference lists of selected publications were screened for missing studies. References of relevant reviews were also checked [16–21].

Quality assessment of studies

Assessment of the methodological quality of the studies included is one of the steps in conducting a systematic review [22]. The concept of quality not only comprises internal validity, but should also contain elements of external validity and information on statistical analysis [23]. One approach in quality assessment is to focus on components of study design, another is to use a criteria list to provide a quality score as an estimation of the overall methodological quality of the design and conduct of the study [24]. However, because of the diversity of observational studies composing a checklist which is generally applicable is not easy [25]. Mostly a set of criteria is developed for the specific population,

intervention and outcome of interest. For this systematic review we adopted and modified criteria from existing quality assessment lists [26–28]. Criteria assessing analysis of confounding variables, selection bias and measurement error were considered essential components, because they may distort the findings of studies. The listed criteria were explicitly described and a pilot test was performed by three reviewers (SvdM, BK, WvdH) on nine articles similar to those included in this review, only with a different type of transplantation, namely heart and lung transplantation. The criteria concerned the study population, measurement of variables related to social participation, influencing factors or determinants and analysis. Additional criteria for case-control and prospective studies were determined.

Two reviewers (SvdM and BK) independently assessed the quality of the studies by rating criteria as positive (+), negative (–), or unknown (?), based on the information provided in the article. Disagreement between the reviewers was discussed during a consensus meeting. If agreement could not be attained, a third reviewer (WvdH) was consulted for a final judgment. For each study a quality score was computed on the subset of internal validity criteria and descriptive criteria separately, as well as a total score. In this way the quality of reporting on the study was not confused with the validity of the studies assessed. A description of the criteria list is given in the Appendix.

Results

Study selection

The literature search in the various databases resulted in the identification of 1794 citations (MEDLINE 944 (52.6%); EMBASE 590 (32.9%); CINAHL 151 (8.4%); PsycINFO 79 (4.4%); International Bibliography of the Social Sciences 11 (0.6%); Cochrane Library 19 (1.1%)).

There was considerable overlap in references identified by the various databases: 46% of references identified by EMBASE were also found in MEDLINE; the same applies for 42% of references found in the Cochrane Library, and also for 35% of references identified by CINAHL.

After removing 351 double references identified by more than one database, a number of 1443 references remained. Of these 1443 references 1079 were excluded based on criteria considering the study population (e.g. children, donors, patients on dialysis, patients on waiting list for kidney transplantation, kidney–pancreas transplantation), the outcome variable studied (e.g. mortality, rejection, infection, compliance, pregnancy, donation procedure, health care organization) or the type of publication (e.g. dissertation abstract, editorial, case report).

After this initial selection 364 references remained. Subsequently, abstracts and articles of these 364 studies were assessed in more detail. Final decision on eligibility resulted in 17 studies which were included in the present review. Reasons for exclusion were related to: the study population ($n = 13$, e.g. patients on dialysis after graft failure were part of study population, patients on waiting list); outcome variable ($n = 154$, e.g. life satisfaction, quality of life, psychological functioning, social support, physical activity, perceived ability to work, employment status as demographic characteristic); data presentation ($n = 46$, e.g. no separate data for (adult) kidney transplantation patients as a subgroup); research report ($n = 116$, e.g. incompleteness as lack of information on age and sex, literature review); follow-up after kidney transplantation ($n = 18$, e.g. measured as total time on renal replacement therapy, lack of information).

Besides the identification of all 17 included studies in the MEDLINE database, 11 were also identified in EMBASE, 1 in CINAHL, 1 in PsycINFO and 1 in the Cochrane Library. Three studies were only identified by MEDLINE [29–31]. Reference checking yielded no additional publications.

Methodological quality

Results of the quality assessment are presented in Table 1. Three studies in which social participation, measured as employment status, was the outcome variable of interest are presented first [32–34]. Other studies which describe indicators of social participation as a kind of background variable or covariate are listed subsequently. The quality scores for internal validity and description

Table 1. Results of methodological quality assessment of 17 studies on social participation after kidney transplantation

| Study reference | Study design | Internal validity criteria IV ^a | | | | | | IV-score | | Descriptive criteria D ^a | | | | | D-score | | Total score | |
|--|--------------|--|---|---|----|---|----|----------|----|-------------------------------------|---|---|---|---|---------|-----|-------------|----|
| | | B | D | F | H | J | L | % | | A | C | E | G | I | % | | % | |
| <i>Social participation as outcome</i> | | | | | | | | | | | | | | | | | | |
| Matas et al. [32] | PR | + | ? | − | + | + | ? | 3/6 | 50 | + | + | ? | + | + | 4/5 | 80 | 7/11 | 64 |
| Markell et al. [33] | CR | − | ? | + | ? | + | NA | 2/5 | 40 | ? | + | + | + | + | 4/5 | 80 | 6/10 | 60 |
| Raiz [34] | CR | ? | ? | + | − | + | NA | 2/5 | 40 | + | + | + | ? | + | 4/5 | 80 | 6/10 | 60 |
| <i>Social participation as covariate</i> | | | | | | | | | | | | | | | | | | |
| Simmons et al. [36] | PR | ? | ? | − | ND | + | + | 2/5 | 40 | + | ? | ? | ? | + | 2/5 | 40 | 4/10 | 40 |
| Russell et al. [37] | PR | ? | ? | − | − | + | + | 2/6 | 33 | + | + | + | + | + | 5/5 | 100 | 7/11 | 64 |
| Flechner et al. [30] | CR | + | ? | − | ND | ? | NA | 1/4 | 25 | + | + | ? | + | + | 4/5 | 80 | 5/9 | 56 |
| Franke et al. [39] | CR | + | ? | − | − | ? | NA | 1/5 | 20 | + | ? | ? | ? | + | 2/5 | 40 | 3/10 | 30 |
| Gross et al. [42] | PR | + | ? | − | AD | ? | − | 1/5 | 20 | + | + | + | ? | + | 4/5 | 80 | 5/10 | 50 |
| Johnson et al. [31] | CR | + | ? | − | − | ? | NA | 1/5 | 20 | + | ? | + | ? | ? | 2/5 | 40 | 3/10 | 30 |
| Baines et al. [38] | PR | ? | ? | − | − | ? | + | 1/6 | 17 | + | + | ? | ? | + | 3/5 | 60 | 4/11 | 36 |
| Gouge et al. [44] | CR | ? | ? | − | − | ? | NA | 0/5 | 0 | + | ? | + | + | + | 4/5 | 80 | 4/10 | 40 |
| Griva et al. [45] | CR | ? | ? | − | − | − | NA | 0/5 | 0 | + | + | + | + | + | 5/5 | 100 | 5/10 | 50 |
| Hathaway et al. [43] | PR | ? | ? | − | ND | ? | ? | 0/5 | 0 | + | ? | + | ? | + | 3/5 | 60 | 3/10 | 30 |
| Koch, Muthny [35] | CR | − | ? | − | − | ? | NA | 0/5 | 0 | ? | + | + | ? | + | 3/5 | 60 | 3/10 | 30 |
| Ostrowski et al. [41] | CR | ? | ? | − | − | ? | NA | 0/5 | 0 | ? | + | + | ? | + | 3/5 | 60 | 3/10 | 30 |
| Taber et al. [40] | CR | ? | ? | − | − | ? | NA | 0/5 | 0 | ? | + | ? | ? | + | 2/5 | 40 | 2/10 | 20 |
| Waiser et al. [29] | CR | − | ? | − | − | ? | NA | 0/5 | 0 | + | + | + | ? | + | 4/5 | 80 | 4/10 | 40 |

^a Methodological quality items are labeled as listed in the Appendix (A, inclusion/exclusion criteria; B, response rate; C, definition participation measure; D, reliability of measurement; E, demographic characteristics; F, association age/gender and participation; G, clinical characteristics; H, association comorbidity and participation; I, data presentation of participation measure; J, controlling for confounding; L, loss to follow-up.

Items are scored as positive (+) or unknown (?). Internal validity items can also be scored as negative (-). Item K is not reported because none of the included studies had a case-control design.

CR = cross-sectional design, PR = prospective design;

ND = no patients with Diabetes Mellitus in study population;

AD = all patients in study population had Diabetes Mellitus;

NA = not applicable.

are presented both separately and as a total method score. The studies are ranked to the score for internal validity as a proportion of the maximum attainable positive criteria and the total amount of applicable criteria for the individual study. If studies have an equal ranking, alphabetical arrangement of the first author's name is applied. Two reviewers scored 172 items and disagreed on 30 items (17%), mostly caused by reading errors, differences in interpretation of the criteria list or unclear reporting in the article. In 37% of the disagreement it considered item B (response rate) and item J (controlling for confounding). The disagreement was resolved in a consensus meeting. In two cases consensus was reached after consultation of a third reviewer (WvdH).

The quality score for internal validity (IV-score) ranged from 0% to 50%, with a median score of 20%. Only one study scored >40% [32]. A shortcoming in the majority of studies was the omission of the response rate or the lack of clarity on it. Three studies reported a response rate <60% (item B) [29, 33, 35]. Likewise, not one study reported on the reliability of questionnaires or interviews used for measurement of indicators of social participation, mostly employment status (item D). Only two studies assessed the effect of demographic factors (sex and age) on social participation (item F) [33, 34]. Effect of diabetes mellitus was assessed in one study (item H) [32] and adjustment for confounding was applied in five studies (item J) [32–34, 36, 37]. Eleven studies had a cross-sectional design. Of the six prospective

studies only three reported a loss to follow-up < 20% (item L) [36–38].

Regarding the descriptive criteria, assessment of the selected studies resulted in a quality score (D-score) ranging from 40% to 100%, with a median of 80%. Most studies described in- and exclusion criteria for the study population (item A) and gave a satisfactory description of the definition and operationalization of the variable considering social participation, which usually was measured as employment status (item C). However, six studies did not describe educational level of the study participants (item E) [30, 32, 36, 38–40]. Furthermore, 11 studies provided insufficient information on clinical variables such as comorbidity (presence of diabetes mellitus) [29, 34, 35, 38, 40, 41], type of donation (cadaveric or living) [29, 35, 36, 41, 42] and dialysis before transplantation (item G) [29, 31, 36, 39, 40, 42, 43]. With respect to data presentation one study omitted reporting information on a relevant indicator of social participation (item I) [31].

The overall quality score ranged from 20% to 64% with a median score of 40%. The relatively poor internal validity was counterbalanced by the higher scores on descriptive quality. Because many studies lacked sufficient descriptive information it was difficult and sometimes not possible to determine if bias was actually present.

Study characteristics

The main characteristics of the selected studies are outlined in Table 2 and grouped in prospective and cross-sectional studies. In three articles the main outcome of the study was an indicator of social participation, operationalized as employment [32–34]. In the other studies employment status was measured as explanatory variable or covariate in relation to outcome variables such as (health-related) quality of life.

Considerable differences in defining categories of employment and the precision of description existed. In some studies students were considered as employed [32, 36], but in others as unemployed [37], or they constituted a separate group [30, 42]. The same applied to homemakers, sometimes marked as unemployed [37], sometimes as employed [31]. This in addition to studies that did not describe how students, homemakers, disabled or

retirees were classified at all [29, 33, 35, 38, 41, 43, 44]. In addition to measuring the post-transplant employment status, the prospective studies compared the status with the pre-transplantation situation [32, 37, 42, 43]. Only Russell et al. [37] tested if the change in employment status is statistically significant. Some cross-sectional studies retrospectively assessed the pre-transplantation employment status [29–31, 33, 34, 41, 44]. Mean duration of return to work was measured in one study [40]. In addition to employment only two studies examined and presented data on other aspects of social participation, for example going on vacation [41] and personal achievements such as taking up new recreational activities and travelling [38].

Considering the study population there was heterogeneity in clinical characteristics. Population size ranged from 20 to 761 patients and only six studies included more than 100 patients [29, 32, 34, 35, 39, 45]. The follow-up period of patients varied between one to more than 10 years after transplantation. Prospective studies had a relatively short follow-up between 1 year [36, 38, 43] to (almost) 3 years [37, 42] after transplantation, with the exception of the study of Matas et al. [32] between 1 to 9 years. Of the cross-sectional studies Flechner et al. [30] described employment status of patients long-term, 10 to 18 years after transplantation. Only four other studies had a long-term follow-up of more than 4 years after transplantation [29, 39, 44, 45].

Other potential relevant demographic and clinical factors in relation to social participation are presented in Table 3. Mean age of the study populations ranged between 27 to 48 years. Some studies presented the mean age of study participants at the time of transplantation [30, 32, 34, 37, 42, 43], while others presented the mean age post-transplantation, at the time of the study. Regarding gender, the proportion of men varied between 45% to 74%. Of the studies that reported on the presence or absence of diabetes mellitus (DM), one study solely included patients with insulin-dependent DM [42], opposed to two studies that excluded patients with DM [36, 43]. As for type of transplantation three studies consisted of recipients of cadaveric kidney transplantation only [31, 38, 39] and one study of living related kidney transplantation recipients [44]. To conclude, three

Table 2. Summary of studies with social participation as outcome (A) and social participation as background variable (B), divided in prospective and cross-sectional studies

| Author, year Country, IV ^a | Aim of study | Outcome (measurement) | Study population | Social participation (measurement) | Follow-up | Results concerning social participation | Employment rate ^b (history) |
|--|---|--|--|--|--|--|---|
| A. Social participation as outcome variable | | | | | | | |
| <i>Results of prospective studies</i> | | | | | | | |
| Matas et al. 1996 [32] USA IV = 50% | Study dynamics of changes in employment after kidney transplantation | Employment patterns (<i>Questionnaire on employment and rehabilitation</i>) | 636 renal transplant patients | Categories of employment (employed, college student, receiving disability benefits, pre-college, other) Full-time work defined as working or attending school full-time (<i>Questionnaire on employment and rehabilitation</i>) | 1–9 years | Pre-transplant employment and non- diabetic status are predictors of return to work post-transplant. Donor source, dialysis and age at transplant are not significant factors | 47% full-time (pre-TX 42%) |
| <i>Results of cross-sectional studies</i> | | | | | | | |
| Markell et al. 1997 [33] USA IV = 40% | Investigation of employment characteristics and effects of education, employment history, insurance type and other parameters on employment status | Employment (<i>Self- constructed questionnaire</i>) | 58 renal transplant patients | Employment activity during past year (employed, unemployed) (<i>Self-constructed questionnaire on employment history, cause of termination of employment, type of health insurance and effect on motivation to work.</i> <i>Job prestige scores according to Cumulative Codebook for General Social Surveys from the Roper Center for Public Opinion Research</i>) | 3.1 years for employed, 1.75 years for unemployed | Pre-transplant employment and time since transplantation (> 1 year) are predictors of employment activity during past year | 43% (pre-TX 50%, before ESRD 81%) |
| Raiz 1997 [34] USA IV = 40% | Examination of relation between health insurance coverage and employment status after renal transplantation, and identification of predictors | Employment status (<i>Self-constructed questionnaire</i>) | 190 primary renal transplant patients | Employment status (employed, unemployed, receiving disability benefits) (<i>Self-constructed questionnaire on ability to work, employment history, attitude towards employment</i>) | > 1 year | Age, race, gender, marital status, receipt of time disability check and pre- transplant employment are predictors of employment status after transplantation | 58% full- or part- time 41% disability benefit (pre-TX 53%, before ESRD 86%) |
| B. Social participation as background variable | | | | | | | |
| <i>Results of prospective studies</i> | | | | | | | |
| Baines et al. 2002 [38] Scotland, United Kingdom IV = 17% | Use of individual psychotherapy after renal transplantation to understand and intervene in emotional issues | Emotional issues and depression (<i>Beck Depression Inventory (BDI) Qualitative measurement through interviews</i>) | 49 primary cadaveric renal transplant patients | Employment status (employed, unemployed) (<i>Interview with themes as employment, social and relationship status, and education</i>) | 1 year | Employment status did not affect depression score Improvement in social interaction, relationships and employment after 1 year psychotherapy | 18% |

Table 2. Continued

| Author, year Country, IV ^a | Aim of study | Outcome (measurement) | Study population | Social participation (measurement) | Follow-up | Results concerning social participation | Employment rate ^b (history) |
|--|---|--|--|---|-----------------|--|--|
| Gross et al. 2000 [42] USA IV = 20% | Evaluation of effects of pancreas transplantation on quality of life compared to kidney transplantation alone | Global and Health-related Quality of life (SF-36 Karnofsky Performance Status Index (KPI), Center for Epidemiologic Studies Depression Scale (CES-D), Health Satisfaction, Index of Well-being, Life Satisfaction, Diabetes Quality of Life (DQOL), Self-constructed questions on benefits and limita- tions of TX) | 87 primary renal transplant patients with insulin-dependent diabetes mellitus | Employment status (employed) (Self-constructed questionnaire on employment and ability to work) | 1 and 3 years | Improvement of most health status and quality of life measures | 1-year: 29%, 3-year: 30% (pre-TX 36%) |
| Hathaway et al. 1998 [43] USA IV = 0% | Identification of predictors of quality of life after kidney transplantation | Quality of life (Sickness Impact Profile (SIP), Ferran and Power Quality of Life Index, Adult Self-Image Scales (ASIS), Per- sonal Resource Questionnaire (PRQ85)) | 91 renal transplant patients | Employment status (employed, unemployed) | 6 and 12 months | In the five prediction models reflecting different dimensions of quality of life, the variables employment, hospitalization and social support are common to all models and account for 20–54% of the variation | 12-months: 51% (pre-TX 58%) |
| Russell et al. 1992 [37] Canada IV = 33% | Measurement of changes in quality of life of patients on dialysis who subsequently underwent renal transplantation | Quality of life (Modified form of Time Trade- Off method (TTO) by interview) | 27 renal transplant patients | Employment status (employed, unemployed) Employed defined as full- time work for a wage or salary (Employment status was determined at second TTO interview) | 31 months | Increase in employment rate of men following transplantation compared with their employment rate during dialysis | men 82% (pre-TX 44%) retirees excluded of analysis |
| Simmons et al. 1988 [36] USA IV = 40% | Comparison of quality of life of patients after kidney transplantation treated with cyclosporine versus patients on conventional immunosuppressive therapy | Quality of life conceptualized as physical, emotional and social well-being (Self-constructed questionnaire on physical and social well-being, Health Satisfaction, Rosenberg Self-esteem and Happiness Scale, Bradburn Happiness item, Campbell Index of Well-being, Index of General Affect, Overall Life Satisfaction, The Quality of American Life) | 91 renal transplant patients | Vocational rehabilitation (working or in school) (Self-constructed questions on employment) | 1 year | Advantage of cyclosporine for subdimensions of quality of life, with a difference in vocational rehabilitation only for women (tentative result because of small number of cases) | men 64% full- time women 31% full-time total 53% full-time |

Results of cross-sectional studies

| | | | | | | | |
|---|---|--|---|--|------------|--|---|
| Flechner et al. 1983 [30] USA IV = 25% | Assessment of quality of life in renal transplant patients with long-term graft survival and comparison with pre-transplant status | Functional capacity and rehabilitation (<i>Interview (face-to-face or telephone) based on self-constructed questions, Karnofsky Activity Scale</i>) | 45 renal transplant patients | Employment and educational status pre- and post-transplant (employed, housework, student, unable to work, unable to attend school) (<i>Interview (face-to-face or telephone) based on self-constructed questions</i>) | > 10 years | Ability of patients to return to work after transplantation | 71% (<i>pre-TX 4%</i>) |
| Franke et al. 1999 [39] Germany IV = 20% | Development of a quality of life questionnaire for end-stage renal disease patients after renal transplantation | Quality of life (<i>SF-36, End-Stage Renal Disease Symptom Checklist-Transplantation Module ESRD-SCL®</i>) | 458 renal transplant patients | Employment status (employed, unemployed, housewife, retired) (<i>Questionnaire</i>) | 78 months | Employment is an indicator of high quality of life in subscales concerning limited physical and cognitive capacity and transplantation-associated psychological distress | 33% |
| Gouge et al. 1990 [44] USA IV = 0% | Examination of quality of life of kidney donors, potential donors and transplant recipients | Quality of life (<i>The Quality of American Life (Life satisfaction subscale)</i> <i>The Structure of Psychological Well-being (Feelings subscale), Affect Balance Scale, Self-constructed questions</i>) | 42 living related renal transplant patients | Employment status before renal failure and post-transplant (employed) (<i>Self-constructed questions</i>) | 57 months | Near normal quality of life in successful living related donor transplant recipients, although employment rate is lower compared to potential donors | 43% full-time (<i>before ESRD 33%</i> <i>full-time</i>) |
| Griva et al. 2002 [45] United Kingdom IV = 0% | Comparison of health-related quality of life and emotional adjustment in living related donor (LRD) and cadaver kidney (CAD) transplant recipients, and identification of factors | Health-related quality of life (HQoL), (<i>SF-36, Transplant Effects Questionnaire (TxEQ)</i>) | 347 renal transplant patients | Employment status (employed, unemployed, retired, looking after home and family) (<i>Self-constructed questions on employment and ability to work</i>) | 8.6 years | More LRD patients are employed than CAD patients, although this difference is most likely attributable to age differences between the groups | 56% full- or part-time |
| Johnson et al. 1982 [31] USA IV = 20% | Assessment and comparison of quality of life between cadaveric transplant recipients and hemodialysis patients | Quality of life (<i>The Quality of American Life (Life satisfaction subscale), The Structure of Psychological Well-being (Feelings subscale), Affect Balance Scale Social network measure, Social Readjustment Rating Scale (SRRS), Self-constructed questions</i>) | 20 cadaveric renal transplant patients | Employment status before renal failure and post-transplant (employed includes housework) (<i>Self-constructed questions</i>) | 46 months | Results of social network measures and SRSS are not presented | 70% full-time (<i>before ESRD 55%</i>) |

Table 2. Continued

| Author, year Country, IV ^a | Aim of study | Outcome (measurement) | Study population | Social participation (measurement) | Follow-up | Results concerning social participation | Employment rate ^b (history) |
|--|---|---|-------------------------------|---|-----------|---|---|
| Koch and Muthny 1990 [35] Germany IV = 0% | Assessment of psychosocial rehabilitation after kidney transplantation and relevant influential factors, and assessment of differences between the treatment groups hemodialysis, peritoneal dialysis and transplantation | Quality of life (Self-constructed questionnaire on satisfaction with life situation and changes after transplantation, and kidney-specific symptom checklist) | 761 renal transplant patients | Vocational rehabilitation (employment status and return to occupation) (Self-constructed questionnaire) | 2 years | Only 8% of patients return to former working place and 7% go in early retirement | 38% full- or part-time |
| Ostrowski et al. 2000 [41] Poland IV = 0% | Evaluation of changes in quality of life after renal transplantation | Quality of life (Self-constructed questionnaire) | 80 renal transplant patients | Employment status before and after transplantation (employed, unemployed) Social life: leisure, holidays, entertainment (Self-constructed questionnaire) | 3.9 years | Improvement in quality of life after transplantation expressed as increase in employment, participation in social life and vacation Mean time to return to work after transplantation is 3.2 months, dissatisfaction in job is reported due to lack or change in promotion opportunities and 14% have lost job after transplantation Results on vacation are not reported | 74% full- or part-time (pre-TX 38% full- or part-time) |
| Taber et al. 1982 [40] United Kingdom IV = 0% | Assessment of quality of life after transplantation compared to that during hemodialysis | Quality of life (Self-constructed schedule for interview) | 50 renal transplant patients | Employment status before and after transplantation, length of time to return to work and promotion opportunities in job Vacation (Self-constructed schedule for interview) | 2.9 years | Mean time to return to work after transplantation is 3.2 months, dissatisfaction in job is reported due to lack or change in promotion opportunities and 14% have lost job after transplantation Results on vacation are not reported | 76% (before ESRD 92%, including students) |
| Waiser et al. 1998 [29] Germany IV = 0% | Comparison of quality of life of renal transplant recipients with patients on dialysis | Quality of Life (Freiburg Somatic Complaint List and Life Satisfaction Questionnaire, Brief Symptom Inventory (short version), SOZU-K-22 questionnaire) | 359 renal transplant patients | Employment status (employed, unemployed) (Questionnaire) | 55 months | Percentage of patients not working remained unchanged after successful renal transplantation | 42% full- or part-time (pre-TX 42%) |

^aIV = internal validity score, range 0–50% (for details see Table 1).^bspecification on full- or part-time employment is described, depending on the availability of this information in the study.
pre-TX, pre-transplantation; ESRD, end-stage renal disease.

Table 3. Demographic and clinical characteristics of study populations of 17 studies on social participation after kidney transplantation

| Authors | Age mean | Sex (% men) | Comorbidity (% DM) | Donor (% CAD) | Pre-TX (% dialysis) | Nr of TX (% > 1) |
|-----------------------|-----------------|-------------|--------------------|---------------|---------------------|------------------|
| Baines et al. [38] | 36 | 45 | – | 100 | 100 | 0 |
| Flechner et al. [30] | 27 ^a | 55 | 0 ^b | 35 | 100 | – |
| Franke et al. [39] | 48 | 55 | 12 | 100 | – | 12 |
| Gouge et al. [44] | 35 | 50 | 17 | 0 | 100 | – |
| Griva et al. [45] | 47 | 54 | 8 | 78 | 92 | – |
| Gross et al. [42] | 39 ^a | 52 | 100 | – | – | 0 |
| Hathaway et al. [43] | 39 ^a | 71 | 0 ^b | 77 | – | – |
| Johnson et al. [31] | 34 | 55 | 10 | 100 | – | – |
| Koch and Muthny [35] | 44 | 59 | – | – | 100 | 11 |
| Markell et al. [33] | 43 | 48 | 9 ^b | 84 | 95 | – |
| Matas et al. [32] | 41 ^a | 62 | 33 | 43 | 80 | – |
| Ostrowski et al. [41] | (18–60) | 63 | – | – | 100 | – |
| Raiz [34] | 40 ^a | 53 | – | 48 | 79 | 0 |
| Russell et al. [37] | 42 ^a | 74 | 7 ^b | 89 | 100 | – |
| Simmons et al. [36] | (19–56) | 65 | 0 | – | – | – |
| Taber [40] | 37 | 60 | – | 98 | – | – |
| Waiser et al. [29] | 48 | 62 | – | – | – | – |

^aage at time of transplantation.^bpercentage of patients with diabetes mellitus (DM) at time of transplantation or DM reported as cause of renal failure.

DM, diabetes mellitus; CAD = cadaveric donor; pre-TX, pre-transplantation; nr of TX, number of transplantations.

– = not reported.

studies only included patients after successful primary kidney transplantation [34, 38, 42].

Interpretation of post-transplantation employment rate as an indicator of social participation showed a rate that ranged from 18% to 82%. Studies reported conflicting results when this rate was compared with pre-transplantation employment rate. Five studies reported an increase in employment rate after transplantation [30, 32, 34, 37, 41], three reported a decrease [33, 42, 43] and one study reported no change [29]. Compared with the situation before the onset of renal disease, two studies reported an increase in employment rate [31, 44], and three studies a decrease [33, 34, 40]. However, in most studies these comparisons were merely described and not tested for statistical significance. The same applied to studies that reported an improvement in participation in social life after transplantation [38, 41].

Predictors of employment status

The three studies with employment status as outcome measure, identified predictors of post-transplant employment status or return to work [32–34].

All three studies determined pre-transplant employment status as a significant predictor of post-transplant employment status. Those patients who worked before transplantation – by Markell et al. [33] described as working either before or during dialysis and by Raiz [34] as working one day prior to transplantation – were more likely to work post-transplant. Findings regarding other factors were less consistent. Raiz [34] identified age as predictor variable and suggested that individuals transplanted at an older age are less likely to be employed. Other studies concluded that age was not a predictor of employment status [32, 33]. Matas et al. [32] described diabetic status as a significant factor, as diabetic kidney recipients were less likely to work post-transplant. Also time since transplantation, defined as more than 1 year post-transplant, was a significant predictor of post-transplant employment status in one study [33]. An other factor identified was receiving a monthly disability check, which was negative related to post-transplant employment status [34]. Two studies reported clinical factors as type of transplant or donor source, and type of renal replacement therapy before transplantation as not significant [32, 34].

Conclusion and discussion

In this systematic review an extensive search strategy was performed to identify observational studies on social participation after kidney transplantation. Of 1443 identified references, eventually 17 studies were selected and the results are summarized in this review. Most studies concern employment status which this review considers as one of the aspects of social participation, however in only three studies it is the main topic and outcome variable. Disappointingly little information on other aspects of social participation is found. The quality assessment revealed considerable shortcomings in data presentation and internal validity, and it is likely that in the 17 selected studies selection and information bias is present. The relative poor quality as well as the issue of heterogeneity, not only in methods of measurement but also regarding characteristics of the study population, makes it difficult to draw firm conclusions on the degree of social participation of patients after kidney transplantation. There is some evidence on influencing factors or predictors, but taking the internal validity of these studies into consideration, these findings must be regarded as tentative. Although most studies are descriptive or exploratory by nature, the external validity or applicability of the findings to other kidney transplantation populations can be discussed. This is for example the case in two studies with a relatively high internal validity score [33, 34]. Despite the relatively high validity score, they lack a clear description of the selection criteria or report a considerable non-response rate through which potential selection bias may exist. Another concern regarding the applicability of the findings to other populations is the mean age of the study populations (range 27–48 years). Study participants in general appear to be younger compared with the total prevalent transplant population, as for example in the United Kingdom the median age of kidney transplant patients was 49.6 years [46].

Outcome measure

Despite the broad and extensive search strategy in which a variety of indicators of social participation was used, the studies we found focus mainly on employment status or return to work. Therefore,

the conclusion can be that research regarding aspects of social participation is nonexistent and if studied the focus is limited. Topics as schooling and education, leisure activities, volunteer work, household activities and social relations, are not well studied. This is remarkable because kidney transplantation nowadays is a routine procedure and treatment of choice for end-stage renal disease (ESRD) [2]. Ultimately, the goal of transplantation is to maximize both the quantity and the quality of life [47]. In other words to enable recipients to return to an active lifestyle, and as a result contribute to a meaningful and productive life.

With regard to the domain of work and employment we found that the definition of employment (e.g. full-time, part-time) and the criteria applied to classify patients as employed (e.g. full-time student, housewife) are often not stated. In addition to this lack of clarity the absence of standardized assessment makes potential information bias likely. As a consequence it is hardly possible to compare the employment rates between the selected studies. Although employment status at first glance appears to be a simple and valid measure, the results of this systematic review indicate the inaccuracy of this assumption.

The aim of this review was the assessment of existing literature on social participation of patients after kidney transplantation, with a focus on actual performance of activities. As a consequence, studies that merely measured the patient's perceived ability or restrictions in social participation, and studies that measured quality of life aspects such as well-being, satisfaction and happiness, were excluded. Regarding employment as indicator of social participation this resulted in exclusion of an often cited study which measured perceived subjective ability to work [48].

Limitations of the review

The first and strenuous part of a systematic review is finding all relevant publications. Because the topic of this review (social participation) is not a medical subject heading in the various computerized databases, as for example quality of life is, we had to compose a search strategy consisting of related terms and keywords. It is possible that this search strategy was not exhaustive. Furthermore,

as we only searched in indexed databases, it is likely that we missed unpublished studies. However, reference checking did not yield additional publications which is an indication of the comprehensiveness of our search strategy. Due to the restriction of references published only in the English language, it is possible that we missed relevant references in other languages.

As a consequence of this broad search strategy a considerable amount of references were found. By applying in- and exclusion criteria we reduced the original set to 17 studies, which in our opinion were relevant for this systematic review. Decisions as to the inclusion or exclusion of individual studies are always to some degree prone to subjectivity [22]. But, to minimize this subjectivity of selection, the eligibility of candidate studies was assessed by two researchers and supervised by a third, if needed.

The assessment of methodological quality as part of a systematic review is widely recommended, but also still a matter of ongoing debate [22]. Most principles of a systematic review are the same for both randomized controlled trials and observational designs [49]. However, there is no validated or widely used criteria list for observational studies available, so we composed a checklist specific for this review. We computed a method score for internal validity and reporting separately, to overcome the problem that positive scores on descriptive criteria compensate shortcomings in internal validity. Still, within the list for internal validity the disadvantage of equal weight for each criterion may lead to high ranking of studies despite major flaws in methodology. Two studies ranked relatively high for example scored both insufficient on 'response rate' and 'analysis of potential confounding of comorbidity' (diabetes mellitus). Not every criterion was able to discriminate between the studies selected. Specifically the criterion for reliability of measurement was scored 'unclear' in all studies. This indicates a lack of standardized and validated instruments used in such clinical studies.

Recommendations

Quality of life in end-stage renal disease patients and after kidney transplantation as specific renal replacement therapy, is a well studied topic as

previous reviews show [6, 16, 17, 19–21]. However, the internal validity of these studies can be discussed based on the quality assessment in this review. The strength of the current review is the use of a systematic approach, in which the selected studies are not only described but their methodological quality is assessed as well. The present study is to our knowledge the first systematic review on a topic related to quality of life after kidney transplantation. It is also the first review with a specific focus on actual performance of activities and participation in daily life situations, as opposed to perceived ability of participation. Employment status appears the common variable of interest in the selected studies. The results of this review show the necessity of a clear definition on employment status and its distinguishing categories. International consensus or guidelines on the accurate measurement of employment status, as well as on other domains of social participation, would make comparison between countries more sensible. Appropriate studies should, besides employment status, also consider other aspects of social participation, as for example leisure activities, volunteer work, schooling and education etc. The International Classification of Functioning, Disability and Health (ICF) [50] may be a useful framework to promote standardized measurement of social participation. This framework also justifies the assessment of relevant environmental factors, such as availability of disability benefits.

It is strongly recommended that future studies fulfil methodological criteria as listed in the quality assessment checklist (Appendix). For reasons of ongoing research in the field of kidney transplantation, it is important to identify potential prognostic demographic, personal and transplant-related factors, and use multivariate regression analysis to adjust for confounding variables. With this knowledge our future ability to identify patients who are at risk for decreased social participation after kidney transplantation may increase.

We state that outcome measures as participation, concerning the social consequences of transplantation, are of major importance in particular in the case of a chronic illness like end-stage renal disease. Not only with regard to the societal and financial efforts involved in kidney transplantation programs, but also for the usefulness of these outcome parameters in decision making regarding

clinical treatment. It is evident that studies from this point of view are still lacking.

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Appendix

Criteria list for the assessment of methodological quality of studies on social participation after kidney transplantation

| Criteria ^b | D/IV ^a |
|---|-------------------|
| <i>Selection of study population</i> | |
| A. Description of inclusion and exclusion criteria | D |
| B. Response rate > 80%, or response rate is 60–80% and non-response is not selective | IV |
| <i>Social participation measures</i> | |
| C. Definition and operationalization of relevant measures of social participation | D |
| D. Reliability of measurement of social participation | IV |
| <i>Determinants of social participation</i> | |
| E. Description of demographic characteristics (age, sex, education) | D |
| F. Examination of relation between age and gender, and social participation | IV |
| G. Description of clinical characteristics (comorbidity, donor, dialysis) | D |
| H. Examination of relation between comorbidity (diabetes mellitus) and social participation | IV |
| <i>Analysis</i> | |
| I. Data presentation of measures of social participation | D |
| J. Controlling for confounding | IV |
| <i>Additional criteria for case-control studies</i> | |
| K. Comparability of cases and controls | IV |
| <i>Additional criteria for prospective studies</i> | |
| L. Loss to follow-up < 20%, or loss to follow-up is not selective | IV |

^aThis column shows if the stated item is: a descriptive or informatory criterion (D) which gives an indication of the external validity or applicability of the findings; an internal validity criterion (IV) which gives an indication of selection bias, measurement error and confounding.

^bScoring of criteria: descriptive criteria were scored as positive (+) if sufficient information was presented; unknown (?) if information was not presented, information was insufficient or unclear. Internal validity criteria were scored as positive (+) if the criterion was met and bias was considered unlikely; negative (–) if the criterion was not met and (potential risk of) bias existed; unknown (?) if information was not presented, information was insufficient or unclear.

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